

A quiet revolution: Exploring user-led research

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# Introduction

In 2021 – 2022, Shaping Our Lives and King’s College London worked together over 16 months on a study funded by the Economic & Social Research Council (ESRC). The study was to test and model effective research partnerships with user-led organisations, and led to the [Matchmaking in Research report](https://shapingourlives.org.uk/report/match-making-in-research/), published in February 2023.

Following that publication, Peter Beresford, who is Chair of Shaping Our Lives and was a contributor to the project with King’s College, wrote a series of blogs exploring different themes relating to the study. The blogs are drawn together in this report. The aim of these blogs is to offer an introduction, not just to the project, but to research and our involvement in research as service users, survivors, disabled people – more generally – and to try and make this as clear and readable as possible.

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# Research made simple

## Keep it simple!

I believe in keeping things simple. Or as one brilliant research officer we used to work with once said to us, “KISS – keep it simple stupid!” There is no better advice. Research can get very complicated. Or put it another way, some people seem to be good at making it as complicated, inaccessible and frightening as possible. We want to do the opposite – and for a very good reason. If people in difficult situations or who have had difficult lives, are kept frightened and uncertain, they will for sure be even more disempowered. And that means other people will be more able to abuse and manipulate them. The whole point of Shaping Our Lives is to do the opposite and to challenge that by enabling people to speak and act for themselves. We believe that getting a grip on research is part of this.

Let me explain. Research is often made obscure, difficult to understand, incomprehensible, even irrelevant. Some people say all it does is grow dusty on library shelves. And sometimes that’s true. But research is also used to control people, to frighten them, and to give more power and authority to people in control. That can’t be a good thing. Researchers may tell us that some fact or opinion has been proved by research and is therefore that much more true and right.  And if we don’t know much about research, then it is very difficult to disagree with them and show they are wrong.

Two helpful points here to reassure you. When I was first doing a PhD – a big research study – my supervisor said to me that if he read something, some book or journal article, and he couldn’t understand it, then he just thought it was rubbish and ignored it. I didn’t like to point out that he was a world-famous sociologist but I was just a student and I doubt if anyone would have been impressed if I had used that argument. But he was right. I learned to show things I’d written to my mother. She came from an immigrant family and had left school at 14. So I thought if she could understand what I had written, then probably it was reasonably clear and reasonably sensible. It was a very good rule and I’ve tried to keep to something similar since. So when you read something, do your best to understand what’s in front of you, but if it still isn’t clear, blame the author, not yourself (but maybe just think that quietly to yourself!).

Of course, you can make anything complicated and difficult if you want to, but here my aim is to keep things simple. Not to oversimplify, but to try and be clear for as many people as possible. Obviously, people who can’t read or have other access requirements, will need those to be addressed as well. We try and do that in Shaping Our Lives routinely.

## What is research?

Now let’s get back to research. Let’s be clear about what research is. It means finding things out. Getting new information and knowledge, or information and knowledge that hasn’t been available to you. It also tends to mean trying to do this in as careful and reliable a way as possible, so you can trust what you find out. But one of the things research soon reminds you, is that there isn’t necessarily one simple truth. Different people see things differently. Different vantage points result in different things emerging or coming to be known.

I want to end this first section by highlighting one thing. Research tends to be a good idea. It isn’t generally a waste of time, as some people think – unless people are demanding more research to delay and stop anything useful being done about a problem we really already know about – like global warming.

To put it simply, it’s really like the old saying: ‘Time spent in reconnaissance (checking things out) is seldom wasted’. Which is a bit like what wood and metal workers say: ‘Check your measurements and mark-up before you cut anything. You can change things once you do that. Once you’ve cut you’ve cut!’ So find things out carefully before acting. Of course, there’s loads more to research as there is to any human activity. But essentially it is just about trying to find things out reliably and accurately.

In the next section we will get down to a bit more detail about the Shaping Our Lives/King’s College London research project. But again, I will try and keep it clear and straightforward and not assume you have lots of knowledge about research.

# ****A chance to develop a research partnership****

## Something special

This is a story about a research collaboration; a collaboration between a university and a service user led/disabled people’s organization or what people call a ULO or DPLO – a disabled people led organisation. This may not seem a remarkable event, perhaps nothing to write home about. But I would suggest it is worthy of note and of looking at more closely for at least four big reasons.

* First, such collaborations aren’t actually very common and frequently go wrong.
* Second, they are important because they challenge many of the divisions that can have damaging effects for us all in society, by privileging what some people know and devaluing the knowledge of others.
* Third, there are likely to be more such partnerships with all the talk of user involvement and coproduction – or at least there should be.
* And, fourth and finally, because of the growing recognition that if we don’t find ways to include people’s different understandings and perspectives in finding things out and creating knowledge, then we will only ever get a partial, biased picture that may never tell us the whole story and also discriminate against some people.

## A great opportunity

This was a research collaboration between Shaping Our Lives, the national user-led organization committed to increasing the say and control of disabled people and service users, and the Nursing School at King’s College London, a leading British research university with an interest in working more closely with service users and our organisations. We were very lucky, we managed to get funding for a collaborative project from the government funder of social science research - the Economic and Social Research Council. More to the point, this was a source of funding reserved for such collaborations, in this case between an academic and service-user organisation – and there aren’t many such special pots of money.

It was a great opportunity and looking back I think we all worked hard to make the most of it. Of course, it wasn’t all plain sailing – we are talking about human beings here, not people with super powers – but in my opinion we have all learned as much from what didn’t work out, as well as what did. And like all good research we did learn many new things.

## Building knowledge

You can read about the project in much more detail in the full report which Shaping Our Lives has produced, [Match Making In Research](https://shapingourlives.org.uk/report/match-making-in-research/), but hopefully here you can get a picture in bite-sized chunks that puts it in its broader context. This is the context of disabled people’s and social care service users’ efforts to develop our own knowledges and undertake our own research in a world where historically other people have often shaped these things for us, not necessarily in our best interests. They have decided who we are, what we are capable of, often making really big decisions that can affect us badly. If there is one thing we know from the development of ‘new social movements’ based on who people are and the discriminations that they face, like the women’s, Black and minoritized people’s and LBGTQ+ movements, it is that people really want to decide for themselves who they are and what they want in life.

In the project’s report, we call our collaboration ‘partnership working’. That report shares the learnings about partnership working between Shaping Our Lives and King’s College London. The guide focuses on the challenges of this type of partnership and how to make the most of the opportunity of bringing a user-led organisation and university research team together to complete a research study.

Not surprisingly, the project raised all kinds of issues for all of us involved – disabled people and service users, academics and researchers – and those sharing both identities. The aim of this series of blogs is to try to think through the learning we all gained from this experience so it can be helpful to others making similar journeys. Obviously, circumstances are likely to vary; different projects and people will doubtless encounter different issues and problems, but we need to build knowledge about these developing roles, relationships and activities, without being prescriptive. That is our aim here and we’ll up the thread in the next section.

# Starting with history

We’d started to talk about research and next I want to go on to tell you more about this research partnership between Shaping Our Lives and King’s College London. I want to do that by putting it in context.

Historically research that has been valued has been carried out in universities or research institutions by university researchers and the like. This is where the high status research has been undertaken, very much, if we are honest, by important-seeming white men in white coats. There have always been built-in biases, because research like everything else reflects the times it is carried out in and the values and assumptions of such ages.

First, it was carried out in the natural sciences – physics, biology, chemistry and so on and then in the arts and social sciences, that is areas like economics, sociology and cultural studies. But that emphasis on science, scientists, experiments and experts has remained. That’s perhaps why people make jokes that we need a researcher to tell us if something is true, it is not enough to think or know it ourselves. And indeed, there is some truth in that. Research is seen as a field of expertise and experts and, as a result, for many people it continues to be mysterious, frightening and indecipherable. And the fact that often it is associated with big words and lots of numbers has encouraged this. And of course there has been that element of other people telling us, as if we couldn’t know for ourselves.

## A quiet revolution

But over recent years there has been a quiet revolution in research. People have challenged the power of old research and its authority. People and groups who feel that it has been used to misrepresent them, their lives and identity, make them out as inferior and/or deviant; from women and Black and minoritized people, to disabled and LGBTQ+ people, have all contested taken for granted research findings about them and moreover begun to carry out their own research and demand the chance to do more of this.

But this revolution is far from over. Rather we are still in the middle of it. Progress is being made, but there is also powerful resistance. Partly this is just the inertia that stops things changing. As they say it is like getting a massive oil tanker to change direction. But there are lots of other barriers in the way. These are barriers to do with getting used to doing things differently, not wanting to do things differently(!), actively resisting doing things differently, wanting to keep your own power and also needing to make a whole range of changes if we are to do things differently! It is quite a list and hopefully during the course of this series of blogs I will be able both to highlight some of these blocks and difficulties and suggest how we may overcome them.

## A service user researcher

Just one last thing before we get down to detail, I should say just a little about myself, so you know where I am coming from and can make your own decision about how much notice to take of what I’ve got to say. That’s something I’ve certainly learned to do as I’ve gained more confidence as both a researcher and a service user.

That is how I identify – as a service user researcher. It’s not necessarily a comfortable badge to wear, but I have to say I wear it with increasing pride. My background is as a long-term user of mental health services – I like to identify as a psychiatric system survivor and someone who has been fortunate to go through training to become a researcher, but a researcher coming from a service user/survivor perspective. For me the two are indivisible. I’ve worked as an academic and researcher, an educator and also spent years on benefits, which as many readers will know is an experience that deserves its own medals!

However, the two worlds I have inhabited – being a service user and a researcher – traditionally, have not often been encouraged to sit comfortably together. That’s why the partnership research initiative between Shaping Our Lives and King’s College London is so important. For us it has been a demonstration project for trying to make that happen, the difficulties to be encountered and how we can deal with them. In my opinion, this is something vital for research and knowledge development for the future.

# A different kind of research

While it might not be an obvious priority for groups facing oppression, research has long been a concern of the disabled people’s and mental health service user/survivor movements. This is because research tends to be associated with producing the ‘official’ knowledge and evidence about people and things. Policymakers and politicians may not act on research but they are more likely to believe what it says than any individual or group with lived experience.

So, in the 1960s and 1970s when some disabled people in residential services wanted to live ordinary lives alongside non-disabled people in ‘the community’ and no one believed that they would be able to, they had the bright idea of calling researchers in to show that they really could. ([Learn more about this famous case](https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-glasgow-lecture.pdf).) It became famous because the researchers from the Tavistock Institute concluded that they couldn’t and said that they would instead always be ‘social parasites’. The disabled people involved in turn called them ‘parasites’ for just confirming the official non-disabled view and vowed that in future they would carry out their own research.

And this is exactly what has happened since, under headings like emancipatory disability research, user-led research and survivor research. All these put a very different meaning on research, how you should do it and the principles that should shape it. It is important to understand this difference in any discussion of research or a particular research project.

Traditionally research has emphasized its ‘scientific’ basis. It isn’t just a matter of opinion, one particular point of view or individual conclusion. Its advocates have always highlighted that this is the most authoritative way of generating knowledge. It is done according to particular clear and agreed rules and in a systematic, rigorous and replicable way. It’s long been claimed that research tells objective truths; it is independent, objective and distanced from its subject.

All this sounds positive and reassuring – it’s not just someone trying to sell us a particular view, or their prejudices. But yet looking back at the conclusions of the Tavistock study, we know now how wrong they got it with their traditional research. Disabled people can live in the mainstream. With the right kind of support they can do most of the things it was said they couldn’t. They certainly don’t have to be and aren’t dismissible as parasites. What is crucial here is not putting barriers in their way and excluding them. This has all since been proved by research.

Moreover, service users, starting with disabled people, came up with a fresh set of principles for their new emancipatory, user-led research. These make it absolutely clear that the fundamental purpose of research as far as they are concerned is to improve the lives of the people with and by whom research is undertaken. Thus, the principles set out that:

* The relation between researchers and researched should be equal
* Research should support the empowerment of research participants
* The aim of research should be to bring about change in line with securing the rights and interests of research participants and people like them.

So research is about making positive change, treating people as equals and improving people’s lives. It is not based on abstract ideas of the neutrality or ‘scientific’ nature of research, but its ability to generate knowledge that can lead to self-defined improvements at personal and political levels bringing about change.

This is not about a special group claiming to be experts and making claims to be superior knowledge creators as ‘scientists’. It is about people working together to develop the knowledge for self-defined reform and rethinking. Research isn’t just a technical exercise – it is a political one too. And it is this recognition of that fact which has created some of the biggest arguments and disagreements seen in research for many years. This is a point we need to take with us on this journey of trying to make sense both of the specific research project jointly undertaken together by Shaping Our Lives and King’s College London and of research much more generally and why it makes for added complexities.

# User led research meets traditional research: lessons to learn

I’ve always thought a key reason why we got funding for this project was because it connected with something seen as important, that is Elinor Ostrom and her principles for collaborative group working and the collective management of resources (natural and other).

Now I’m not saying she hadn’t got something helpful to say and of course unlike you or me(!!) she got a Nobel prize, so she is seen as up there with the giants.

Together we wanted over the 16 months’ course of the research to investigate new ways of partnership working between researchers, disabled people and health and social care organisations. Our Big Lottery Inclusive Involvement Movement project group could offer a potentially innovative case study to apply Ostrom’s principles. (For more detail on the research project, see our [Research Report](https://shapingourlives.org.uk/report/match-making-in-research/).)

But in my opinion at least, far more important than exploring user-led work in relation to Ostrom’s principles as was intended, is to develop the analysis of the new self-research pioneered by a wide range of people from feminists, environmentalists, disabled people and the LBGTQ+ community. This has been an unbelievably ground-breaking development, rethinking the purpose, nature, aims, relationships and role of research and highlighting diverse kinds and sources of knowledge.

I don’t think the mainstream research world yet sees disabled people’s or service users’ research as important in its own right, or at least not as important as it needs to be. So, our route in effect had to be to attach ourselves to an historic researcher. At the end of the day, I don’t think we learned much new from her. And really in my view this is looking through the wrong end of the telescope. Mainstream research needs to be looking to us for new ideas, methods and methodology, not the other way round.

But I guess this is how processes of change work; often too slowly for the innovators, but projects like King’s College London and ours do signify and help legitimate such change.

## ****We truly all are different – don’t forget that!****

We should also remember that there are not only differences of opinion between academics and service users, but also that as service users, we may not all be coming from the same place and we need to recognize and think through any differences in our viewpoints. The aim should not be to force people into some artificial consensus, but to surface and explore competing understandings and opinions. This is another way in which we can all learn and achieve better results as well. We won’t all start from the same point of view and we need to remember this. In our report of the research project we talked about ‘making sure that everyone is on the bus’. This is a helpful down to earth way of making sure we don’t forget this important issue and allow time for everyone to catch up and get on that bus!

We learned it was important to clarify our different roles in the research project. For example, as a user-led organization, we would not expect a university to influence how we proceeded with our organisation, although insights that could be offered through the research could be helpful. But it is hardly surprising that confusions and ambiguities like this cropped up during the project, for all our mutual goodwill. We were all entering uncharted territory. We didn’t have much history to learn from! That’s something we need to build, and that’s what comes next.

# Learning from our different experience

Shaping Our Lives’ collaboration with King’s College London was a positive learning experience in very many ways. We were lucky we worked with a partner whose heart was in the right place, who like us wanted to see an equal partnership work and we had some lead-in time to get to know each other. But still it wasn’t easy and there were confusions, between us and among us. So really what is needed if inclusive, collaborative research like this is to work is some initial funding from research funders to help us get to know each other to work best together – before we even properly start. At present that rarely happens unfortunately, but funding early on would avoid many difficulties later on.

## ****More inclusive funding****

That brings us to the whole bigger issue of funding. We were very lucky we got funding from a special pot of high-status money intended for just such partnerships. But there are few of these on the ground.

There really needs to be a ground up review of research funding to keep pace with big changes that have taken place in research in recent years. Until that happens user-led research and partnerships like ours will not get the support they need. We must have a more inclusive approach to research funding that innovates and experiments and enables newer players to get involved.

## ****Inclusion****

If we are serious about inclusive research; that is to say, research which truly challenges routine exclusions around issues of age, impairment, distress, gender, sexuality, ethnicity and so on, then we must recognize that inclusion often costs money. It’s needed to ensure accessible environments, communication and the additional time that’s often needed to get people up to speed. That money needs routinely to be included in grant giving. Otherwise for all the talk of ‘protected identities’ and challenging discrimination, funders and researchers will perpetuate traditional exclusions and only ever get part of the picture.

## ****More support for service user researchers****

The worker on this research did not identity as a service user or disabled person. We wanted to recruit someone with lived experience but were unable to. This highlights the fact that while more disabled people and service users are now undertaking research training, enlisting on PhDs and so on, they are still a relatively small number overall. Much more support needs to be made available for service user researchers so that they can take on the increasing number of research jobs where their experiential knowledge is at a particular premium.

## ****From elitist to inclusive universities****

Universities have always been concerned with being powerhouses of knowledge, drawing together ‘the brightest and the best’ to advance society through developing prestigious education and knowledge. This sits rather uncomfortably with the mission of movements like the survivors, disabled people’s and service user movements and organisations like Shaping Our Lives, committed to achieving the full citizenship of groups often marginalized and seen as inferior, whose knowledge is routinely devalued.

This pressure on universities to be elite institutions, to be seen to compete on a world stage, has grown over the years, with increasing competition imposed on them through developments like the Research Excellence Framework (REF), overshadowing the lives of academics, however much they want to be part of and a supportive resource for their communities and those who live in them. We all have to recognize this tension and work to challenge it, remembering that universities are also meant to involve their local communities, to achieve change and to support participation in their research and learning. We have to learn the best ways to press these buttons!

# Tips for the future

In the Shaping Our lives report on the research project, we offer many tips for taking such equal collaborative research projects forward for the future. They seem really helpful and they build on the body of experience that this partnership offered us. But – and it can be a big but – they are easier said than done at present. Much more needs to be happening at a more structural level, to include service user research and researchers, in all their diversity, on equal terms. We need our allies in universities and research organisations to join us in pressing hard for this. But these are lean times in public policy, services and organisations, with many years now of unremitting cuts.

I doubt we will see the true contribution for full user involvement and partnership in research until our present national formal politics change and move on from small state neoliberalism, to a more truly mixed economy and rights-led and sustainable society. These are big changes but partnership research like that we are discussing here can have a helpful role in making this happen, rather than just being seen as a victim of present market-driven ideology.

## Access and the pandemic

Because of the pandemic, the project was carried out remotely. This can be seen as having strengths and weaknesses. Certainly, from my point of view, for example, the absence of travel, made things easier. But we should not assume that the same is true for everyone. There are both gains and losses from working remotely as there are, particularly for many disabled people with access needs, with face-to-face working. So far there is little sign that this big lesson is being learned and that ways of research working are including the strengths of each working style, rather than perpetuating the barriers associated with each.

## ****The importance of trust; the centrality of building relationships****

We were lucky in our relationship with academics from King’s College London. There seemed to be a preparedness to listen and learn from us and a respect that provided a real starting point for building trust and relationships in our work together. User involvement in research and participatory research receive a lot of positive rhetoric, but too often the reality is much more stressful and difficult, with tokenism a routine and regular concern of user-led organisations like Shaping Our Lives. There was trust between the two parties in this arrangement, but then we all worked hard to make it possible and when there were problems or misunderstandings, tried to sort them out. No one is saying it is easy, but it is possible and as this happens more often and more routinely, so hopefully it will become more straightforward for all of us.

Meanwhile if there’s one saying that stayed helpful during this experience, for me at least, it was articulate the issue. If you have a worry, something isn’t going as it should be, or there seem to be unstated differences, say so. Don’t leave misunderstandings or differences of opinion to fester and cause real damage. Open, accessible, regular communication is at the heart of sorting this. Shaping Our Lives estimated it took a year to build up the trust and working practices that worked for everyone.

We hope that our experience will help many others, both academic researchers and service user researchers. We also hope that increasingly there will emerge a body of researchers, blessed with both sets of skill and experience. They will be a powerhouse for more inclusive and participatory research and knowledge development.

That’s one of my real hopes for the future.

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